

University of Groningen

## The role of the general practitioner during treatment and follow-up of patients with breast cancer

Roorda-Lukkien, Carriene

**IMPORTANT NOTE:** You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

### *Document Version*

Publisher's PDF, also known as Version of record

### *Publication date:*

2015

[Link to publication in University of Groningen/UMCG research database](#)

### *Citation for published version (APA):*

Roorda-Lukkien, C. (2015). *The role of the general practitioner during treatment and follow-up of patients with breast cancer*. [Thesis fully internal (DIV), University of Groningen]. [S.n.].

### **Copyright**

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

### **Take-down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

---

# CHAPTER 6

## Patients' perceptions about the aims of breast cancer follow-up

*Submitted for publication*

Carriene Roorda<sup>1,2</sup>, Annette J.  
Berendsen<sup>1</sup>, Christian Scholing<sup>1</sup>,  
Liesbeth Jansen<sup>3</sup>, Marlieke de  
Fouw,<sup>1</sup> Marjolein Y. Berger<sup>1</sup>, and  
Geertruida H. de Bock<sup>2</sup>

University of Groningen,  
University Medical Center  
Groningen  
Departments of <sup>1</sup>General  
Practice, <sup>2</sup>Epidemiology, and  
<sup>3</sup>Surgical Oncology



## ABSTRACT

*Objective* The objective of this analysis was to describe patients' perceptions of the aims of breast cancer follow-up.

*Methods* Semi-structured interview data from 61 female patients with a history of early-stage breast cancer were used. By means of descriptive content analysis with qualitative and quantitative elements, patients' verbatim responses were analysed independently and thematically by two researchers.

*Findings* Among the patients, detecting recurrent breast cancer (n=40) and providing reassurance (n=29) were the most frequently reported aims of follow-up. Less frequently mentioned aims were: providing psychological support, evaluating care, generating hospitals' income, and providing wound care. Differing and sometimes unrealistic beliefs were observed regarding the risk of developing recurrences and the effectiveness of follow-up to detect these recurrences. Patients aged  $\leq 60$  years more often considered reassurance as an aim of follow-up than patients aged  $> 60$  years [17/24 vs. 12/37; Chi-square test  $p < 0.01$ ]. Despite the perceived psychological advantage of receiving reassurance, patients also reported disadvantages in terms of experiencing anxiety and being confronted again with their breast cancer history.

*Conclusions* To avoid unrealistic beliefs and expectations among patients, educating them about the aims and the evidence underlying follow-up might be important. Furthermore, possible fear of recurrence should be addressed, especially among younger patients.

## INTRODUCTION

Breast cancer is the most common malignancy and the leading cause of cancer-related death among women worldwide<sup>8</sup> as well as among European women.<sup>9</sup> Survival rates of female breast cancer have increased in many countries as a result of early detection by mammography and improved treatment.<sup>8,9</sup> However, breast cancer survivors are at risk for recurrences and second breast carcinomas for 20 years or more.<sup>24</sup> Although most of them will report a good quality of life over time, they may experience specific symptoms or problems related to breast cancer and its treatment.<sup>25-27</sup> Therefore, routine follow-up after completion of primary treatment is recommended. The aims of this follow-up are to detect loco-regional recurrences at an early stage, to monitor treatment-related side-effects, to provide psychological support, and to collect data for evaluation of care.<sup>7,45</sup>

Surveillance mammography is recommended to detect both loco-regional recurrences and contralateral breast carcinomas at an early stage.<sup>24</sup> Although most guidelines also recommend follow-up visits for history taking and physical examination,<sup>7,46,47</sup> the contribution of physical examination to the early detection of recurrences is uncertain since most relapses are detected by the patients themselves or by mammography.<sup>48,49</sup> Guidelines vary not only with respect to the frequency and duration of follow-up visits, but also regarding which care provider should perform the follow-up,<sup>7,46,47</sup> as the optimal approach is not established.<sup>50</sup> Additional investigations [e.g. blood tests, chest X-ray, and MRI] for detection of distant metastases are not recommended, since these investigations do not lead to improved survival of patients with a history of breast cancer.<sup>24,45</sup> Nevertheless, two quantitative surveys on patients' needs and preferences revealed that patients with a history of breast cancer expect to have a greater chance of survival by detecting distant metastases at an early stage and by undergoing additional investigations.<sup>88,90</sup> These findings may suggest that they lack information on the primary goals and potential benefits of follow-up.<sup>88</sup>

Little research has been performed on how patients with a history of breast cancer perceive the aims of post-treatment follow-up. In a survey among patients in the UK (n=79), the most frequently mentioned reasons for follow-up visits were detection of relapse (68%) and provision of reassurance (30%).<sup>139</sup> In a qualitative study, patients in the Netherlands considered examination of the breast and reassurance to be the main purposes of follow-up.<sup>143</sup> We conducted a qualitative study to describe patients' preferences for follow-up in primary care vs. secondary care.<sup>144</sup> This second analysis of the semi-structured interview data attempts to provide a deeper understanding of patients' perceptions of the aims of breast cancer follow-up.

## METHODS

The setting of the qualitative study, recruitment of patients, interview guide development, and data collection are described in detail elsewhere.<sup>144</sup> At the time this study was conducted, five years of hospital follow-up was recommended for all women in the Netherlands curatively treated for breast cancer. After five years, younger women (aged  $\leq 60$  years) were to continue with hospital follow-up, while older women (aged  $> 60$  years) were to be referred to the national screening programme (when treated with mastectomy) or their GP (when treated with breast-conserving therapy).<sup>33</sup>

Semi-structured interview data from female patients with a history of early-stage breast cancer were used. These patients were included in the study by their general practitioner (GP); all the involved GPs were participating in the Registration Network Groningen (RNG). At the start of the study, this general practice research network consisted of three group practices with 17 GPs and a dynamic population of approximately 30 000 patients in the northern part of the Netherlands.<sup>99</sup> According to the Institutional Review Board of the University Medical Center Groningen, no approval was needed for this non-invasive study.<sup>144</sup> To protect patient identity, reference numbers were assigned to the interview data.

Patients who gave their written informed consent were contacted by the researchers. They were interviewed at home (n=69), in general practice (n=2), or at our Department of General Practice (n=1) [Figure 1]. Interviews lasted 30-60 min, were audio-recorded and transcribed verbatim. A semi-structured interview guide was used, including questions about patients' preferences for breast cancer follow-up in primary care vs. secondary care,<sup>144</sup> as well as the open-ended question: "What do you think are the aims of follow-up visits?", to enable patients to elaborate on this topic. This chapter reports on patients' perceptions of the aims of follow-up.

### *Data analysis*

Transcripts of 61 patients were included in the present analysis, because only these patients were eligible and asked the open-ended question about the aims of breast cancer follow-up [Figure 1]. Descriptive statistics were used to describe patients' characteristics. Patients' responses to the open-ended question were coded individually by two researchers using descriptive content analysis.<sup>136</sup> Themes were identified and the researchers discussed any discrepancies in the findings until consensus was reached. Summaries were written and illustrated with quotes from the patients. For the perceived aims of follow-up, the numbers of responses were counted. Furthermore, the Chi-square ( $\chi^2$ ) test was used to evaluate whether 'age at the time of the interview' and 'time since breast cancer diagnosis' were associated with these responses. In this way, descriptive content analysis, with qualitative and quantitative elements, was used in the data analysis.<sup>136</sup>

102

## RESULTS

Characteristics of the included patients are presented in Table 1. Median age at the time of the interview was 62.5 years [range 34.5-88.4]. Median time since breast cancer diagnosis was 7.0 years [range 1.0-23.1]. The most commonly reported aims of follow-up as reported by the patients were: detecting recurrent breast cancer (n=40) and providing reassurance (n=29) [Table 2]. Less frequently mentioned aims were: providing psychological support, evaluating care, generating hospitals' income, and providing wound care.

### *Detecting recurrent breast cancer*

Although most patients did not specifically distinguish between loco-regional recurrences, contralateral primaries, or distant metastases, some patients explicitly mentioned ‘surveillance of metastatic disease’ as an aim of follow-up:

*Well, it's only to do with whether or not you have cancer again or metastases or something like that? Otherwise it doesn't have any further use... [P07, age 86 years].*

Certain patients expressed their beliefs about the risk of developing a recurrence. Some patients were informed that women with a history of breast cancer had a higher risk of developing breast cancer than women without breast cancer and/or that recurrences could still develop after a long time. Other patients believed that breast cancer could not come back after 2-5 years of follow-up and/or that recurrences could not develop directly after, or in between, follow-up appointments.

103

*Because it can always come back again... I once heard it said: that someone who has had breast cancer is more sensitive for a second time. But I don't know if that's true [P13, age 79 years].*

*...Once that five-year period is over, I don't think it's necessary any more. Then I assume it's clean and that it won't come back - also not in other places... [P60, age 70 years].*

Some patients had doubts about the effectiveness of routine follow-up to detect recurrences. They stated that follow-up visits would be only ‘snapshots’ and that patients might also come to the clinic after experiencing symptoms. Furthermore, they questioned the sensitivity of physical examination and mammography to detect recurrences and mentioned the possibility of false-negative results. However, other patients explicitly valued mammography and would like to see additional investigations to be part of their follow-up visits.

*Yes, really it's just nonsense, if you think about it properly ... But if someone gets complaints, and then comes for a check-up, then you get those back too. So that's a kind of false security, that you're still getting check-ups [P28, age 39 years].*

*...My sister gets an MRI every year. And in my case it's just a mammography... I don't like the MRI at all - but then just let me have an MRI.. “ [P40, age 50 years].*

### **Providing reassurance**

With respect to 'providing reassurance', patients wanted to be told by hospital staff that 'everything was [still] all right', that 'nothing was going wrong', and that 'they were disease-free'. After receiving the 'good news' they expressed feelings of relief, calmness and happiness, while some patients said that they had confidence (in their own body) again. Reassurance was not only gained from 'good' test results but was also related to the expertise of the hospital [oncological] staff. Patients aged  $\leq 60$  years more often considered reassurance as an aim of follow-up than patients aged  $>60$  years (17/24 vs. 12/37;  $\chi^2$  test  $p < 0.01$ ) [Table 3].

104

*...I've been let down by my body so many times that you can't rely on your own body any more. And then - those dates for a check-up - really were a form of security for me... [P27, age 59 years].*

*But here they really are experts - and that feels very safe... Because you feel you're walking on quicksand - you don't know what your body's going to do, or which way it's going..." [P51, age 61 years].*

Despite the perceived psychological advantage of feeling reassured after attending the follow-up clinic, disadvantages were also reported by the patients in terms of experiencing anxiety and being confronted again with their breast cancer history. Prior to follow-up visits, patients experienced feelings of uncertainty, nervousness, fear, panic, worry and distress. However, after receiving the 'good' news, in most patients these negative feelings disappeared and were replaced by positive feelings. One patient stat-



ed that she remained anxious between follow-up visits, while another was mainly worried during the first two years of follow-up. Some patients felt that they could not end the story of the breast cancer experience whilst still going to the hospital for regular follow-up visits.

*...Well, I have to go again - later on they'll find something else. And then every three months. And one week before you're already very nervous... then you start to worry again... and then you can't sleep again... [P60, age 70 years].*

*...that I'm being confronted with it again, I feel as though I'll always be a cancer patient. I just want to be a person who once had a sickness... or someone who was confronted with something bad... [P10, age 36 years].*

### **Psychological support**

For patients reporting the aim of 'providing psychological support', talking about the breast cancer experience, discussing breast cancer-related issues, and asking questions at follow-up visits were very important. Some patients explicitly sought support from knowledgeable and experienced people in the hospital, while others mentioned that less time was available at follow-up visits to talk about what had happened since the diagnosis. One patient stated that patients should not expect to receive psychological support from a surgeon (who has less available time for this) but, when required, they should see a psychologist or psychiatrist.

*The human touch... just a bit of attention - from someone who has expertise. Someone who knows what they're talking about and can give some support. Spiritual support to persevere and to be able to carry on... [P02, age 83 years]*

### **Evaluating care**

Patients reporting the aim of 'evaluating care' (n=5) were either told this by their specialist, or themselves thought that patient follow-up is important to see how many new tumours and/or recurrences develop, how patients are doing, and how patients deal with their disease.

*I think they also want to learn about how people have experienced the whole process... and that every person is different... One needs this and the other needs that... [P53, age 69 years]*

## DISCUSSION

This analysis of semi-structured interview data provides a deeper understanding of patients' perceptions of the aims of breast cancer follow-up. Among these patients, detecting recurrent breast cancer and providing reassurance were the most frequently reported aims of follow-up. Less frequently mentioned aims were: providing psychological support, evaluating care, generating hospitals' income, and providing wound care.

In line with the present findings, Montgomery *et al.* [2008] earlier reported that detection of relapse is the most frequently mentioned reason for follow-up visits among patients in the UK. Although most patients in our analysis did not specifically distinguish between loco-regional recurrences, contralateral primaries or distant metastases, some patients explicitly mentioned surveillance of metastatic disease as an aim of follow-up. Furthermore, some valued additional investigations as part of the follow-up visits; however, this is not recommended in the literature.<sup>24,45</sup> The belief that breast cancer could not come back after 2-5 years of follow-up and/or that recurrences could not develop directly after (or in between) follow-up appointments is contrary to the evidence, showing that breast cancer patients have a residual risk of recurrence even after 20 years of follow-up.<sup>24</sup> Moreover, the majority of relapses are detected by the patients themselves or by mammography, when compared with physical examination at follow-up visits.<sup>48,49</sup> Other studies found that patients expect to have a greater chance of survival by detecting metastases at an early stage and by performing additional tests.<sup>88,90</sup> Unrealistic expectations about the benefits of follow-up and additional examinations were also found in another qualitative study among breast cancer patients in the Netherlands.<sup>143</sup> Education about the aims and the evidence underlying follow-up might be important to avoid unrealistic beliefs and expectations among patients.

In the present analysis, >40% of the patients considered reassurance as an aim of follow-up, compared to 30% of patients in the study of Montgomery *et al.* [2008]. These data support other findings that patients with a history of breast cancer perceive reassurance to be an important purpose or psychological advantage of follow-up.<sup>91,92,143,145-147</sup> The relationship with hospital staff, the availability of cancer expertise, and the access to diagnostic investigations provides the greatest reassurance.<sup>91,92,145,146</sup> In the present analysis, patients aged ≤60 years more often considered reassurance as an aim of follow-up than patients aged >60 years; this might be because younger breast cancer survivors report more fear of recurrence than their older counterparts.<sup>148-150</sup> In clinical practice, attention should be paid to possible fear of recurrence, especially among the younger patients.

Despite the perceived psychological advantage of receiving reassurance, patients in the present analysis (as well as in other studies) reported disadvantages of follow-up visits in terms of inducing anxiety in patients<sup>91,92,145-147</sup> and bringing the breast cancer diagnosis to the forefront of their life again.<sup>147</sup> The cycle of emotions described by Allen [2002] was also found in the present analysis, as patients reported anticipatory anxiety before going back to the clinic. This anxiety created a need in the patients to attend the clinic in order to receive reassurance that they were well and disease-free.<sup>145</sup>

In the present analysis, the aims of monitoring treatment-related side-effects, providing psychological support, and evaluating care were mentioned to a much lesser extent or were not mentioned at all, as was also the case in the study of Montgomery *et al.* [2008]. In a survey among breast cancer specialists in the UK, detection of treatment-related sequelae was considered the major reason for follow-up, followed by recognition of new ipsi- or contralateral abnormalities, psychological morbidity and recurrence.<sup>94</sup> It remains uncertain whether follow-up visits contribute significantly to the detection of physical and psychosocial problems.<sup>139</sup> This might be explained by discordant perceptions between patients and

their specialists concerning the aims of follow-up. Another explanation is that patients perceive follow-up visits as being too short to discuss all the information, to ask questions, and to address all their concerns and worries.<sup>91,92,145,147</sup>

A major strength of this analysis is the large sample of participants (n=61), which made it possible to conduct descriptive content analysis with qualitative and quantitative elements. Furthermore, the sample covered the perceptions of women (aged 34-88 years) with a history of breast cancer and still alive at 1-23 years after diagnosis. Although 10 of the initial transcripts were excluded from the analysis due to missing data (Figure 1), we believe that sufficient responses remained to analyse and draw conclusions. A limitation might be that the present analysis was conducted among women already undergoing breast cancer follow-up, who might have established ideas about what they expect from follow-up.<sup>139</sup> However, our results are comparable with those reported by Montgomery *et al.* [2008] who explored the expectations of breast cancer patients prior to their first follow-up visit.

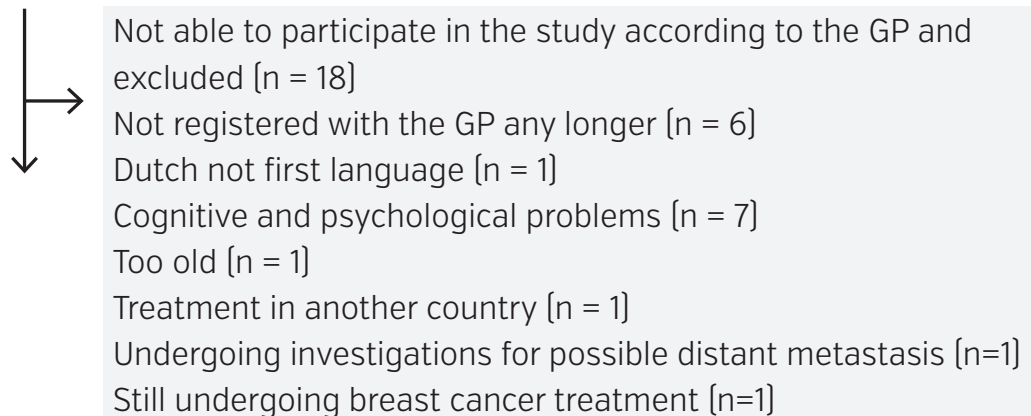
108

In conclusion, from a patient's point of view, surveillance of recurrent disease and providing reassurance appear to be the most important aims of breast cancer follow-up. To avoid unrealistic beliefs and expectations among patients, educating them about the aims and the evidence underlying follow-up might be important. Furthermore, possible fear of recurrence should be addressed, especially among younger patients.

## FIGURE AND TABLES

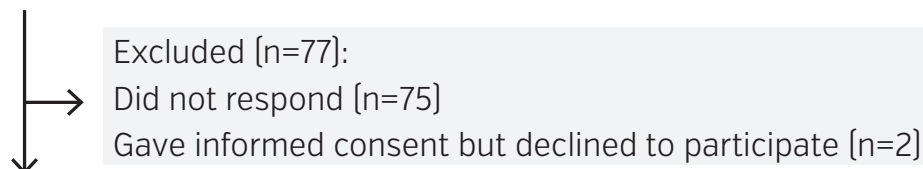
**Figure 1.** Flow diagram of the identification and inclusion of patients with early-stage breast cancer.

Breast cancer in history and registered with a participating GP at the start of study (n = 167)

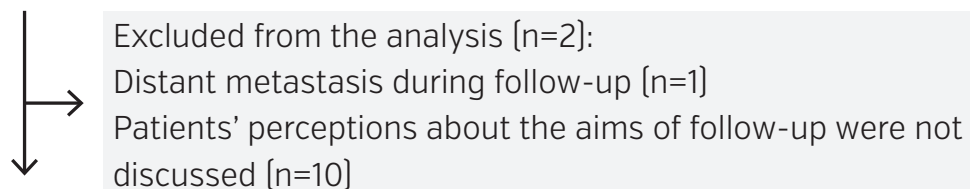


109

Able to participate in the study according to the GP (n=149)



Gave informed consent (n=72) and were interviewed



Included in the analysis (n=61)

**Table 1.** *Characteristics of the patients included in the analysis.*

	N=61
Age at diagnosis, median [range], years	55.4 [27.4-83.9]
Breast cancer T stage, n [%] <sup>a</sup>	
Tis/T1	38 [64.4]
T2/T3/T4	21 [35.6]
Unknown	2
Breast cancer N stage, n [%] <sup>b</sup>	
N0	44 [72.1]
N+	17 [27.9]
Surgery, n [%]	
Lumpectomy <sup>c</sup>	34 [55.7]
Mastectomy <sup>d</sup>	27 [44.3]
Systemic treatment, n [%]	
None	10 [16.4]
Chemotherapy	31 [50.8]
Endocrine therapy	15 [24.6]
Chemotherapy + endocrine therapy	5 [8.2]
Recurrent breast cancer during follow-up, n [%]	
Locoregional	3 [4.9]
Contralateral	1 [1.6]
Age at time of interview, median [range], years	62.5 [34.5-88.4]
Time since diagnosis, median [range], years	7.0 [1.0-23.1]

<sup>a</sup>T stage: type [in situ or invasive] and size of the tumour

<sup>b</sup>N stage: absence or presence of the disease into the regional lymph nodes

<sup>c</sup>Including patients treated with lumpectomy, with and without radiation therapy

<sup>d</sup>Including patients treated with mastectomy, with and without radiation therapy.

**Table 2.** Aims of follow-up, according to the patients (n=61).

	INTERVIEWS, N (%)
Aims of follow-up	
Detecting recurrent breast cancer	40 [65.6]
Providing reassurance	29 [47.5]
Providing psychological support	10 [16.4]
Evaluating care	5 [8.2]
Generating hospitals' income	1 [1.6]
Providing wound care	1 [1.6]

**Table 3.** Most commonly reported aims of follow-up, by age and time since diagnosis.

AIMS OF FOLLOW-UP <sup>A</sup>	INTERVIEWS, N (%)			
	AGE AT TIME OF INTERVIEW (YEARS)		TIME SINCE DIAGNOSIS (YEARS)	
	≤60.0 (N=24)	>60.0 (N=37)	≤5.0 (N=22)	>5.0 (N=39)
Detecting recurrent breast cancer	15 [62.5]	25 [67.6]	15 [68.2]	25 [64.1]
Providing reassurance	17 [70.8]*	12 [32.4]*	10 [45.5]	49 [48.7]

\*Chi-square test  $p < 0.01$

<sup>a</sup>Other aims were not tested due to an expected count of less than five.